

Consent Policy Design Group

Meeting Minutes

MEETING DATE	MEETING TIME	Location
May 7, 2019	1:00PM – 2:00PM	Join Zoom Meeting: https://zoom.us/j/269726549 Dial: +1 646 876 9923 US Meeting ID: 269 726 549

DESIGN GROUP MEMBERS					
Stacy Beck, RN, BSN	x	Susan Israel, MD	x	Nic Scibelli, MSW	x
Pat Checko, DrPH		Rob Rioux, MA	x		
Carrie Grey, MSIA		Rachel Rudnik, JD	x		
SUPPORTING LEADERSHIP					
Allan Hackney, OHS	x	Chris Robinson, CedarBridge	x	Tim Pletcher, Velatura	x
Carol Robinson, CedarBridge		Ross Martin, CedarBridge	x	Lisa Moon, Velatura	x
Michael Matthews, CedarBridge	x				

Minutes			
	Topic	Responsible Party	Time
1.	Welcome and Overview	Michael Matthews	1:00 PM
	<p>Michael Matthews welcomed the workgroup members. He indicated most of the agenda will be led by Velatura. They will review the use case approach. They will lay the groundwork for how consent and the trust framework will be supportive of initial HIE use cases.</p>		
2.	Public Comment	Attendees	1:05 PM
	<p>No public comments at this time.</p>		
3.	Use Case Approach to Sharing Health Data	Velatura	1:10 PM
	<p>Michael Matthews introduced Velatura. Velatura runs one of the best HIEs in the country. They are subject matter experts in this field and come with a wealth of experience in managing consent and operations.</p> <p>Tim Pletcher from Velatura introduced himself. He ran an HIE in Michigan for 9 years. He explained that any authority he has comes from making many mistakes. They have found a handful of things that work really well. One of the key concepts is using use cases. His training is in IT and his whole life has been consumed by different levels of interoperability. His academic background is in health IT and health policy. He has worked in many settings: tertiary, quaternary and at a university. He also teaches at the University of Michigan Medical School on health infrastructure.</p> <p>Lisa Moon from Velatura introduced herself. She is very excited to be here. She is a nursing informaticist. She has worked in health care delivery, at a large national payer, and in state government as an HIE regulator. She also works at the University of Minnesota. Her research is focused on consumers owning their data. She agreed with Tim Pletcher in that they have had plenty of opportunities to make mistakes and have lots of lessons learned.</p> <p>Tim Pletcher indicated there will be 2 sessions to review the legal framework and what they plan to launch for the HIE entity. He indicated that some of what they may talk about today will feel pretty basic, but it may be very healthy to start with principles. He asked the workgroup to please ask questions as they go through the material.</p>		

Tim Pletcher provided a summary of the content for this meeting. They will review push and pull concepts, use case approach, and the legal framework which will then surface questions that they will answer during the next session.

Tim Pletcher discussed models for health information exchange. He indicated that there is a lot of literature in the early days which found many individuals very unsatisfied with HIEs. They would log on to the HIE, look for a patient and not find information on him/her. This idea of having data automatically come to the provider became preferred in terms of provider satisfaction. One of the most successful types of push data comes in the form of alerts. This is when something has happened with the patient and there may be information that is interesting. The holy grail of where people would like to be is pulling data. However, to do this is a higher bar and requires a little more infrastructure, whereas pushing data is simpler and can be controlled better.

Tim Pletcher reviewed a generic situation for an immunization. A person receives a flu shot. This information is pushed through the HIE and the HIE pushes this vaccination information to the immunization registry. The registry is very well-known, and the decision process is pretty simple. The actual pharmacy working with the patient pushes this data to a well-known place. This is predictable and not technologically sophisticated from an HIE perspective. Typically, there is some rule that mandates this information be sent to a registry. Many states start with immunization/public health because it gets the whole system moving and consent is controllable.

Tim Pletcher reviewed a different situation related to alerts. Encounter notifications are the best example. There is a notification that a patient is in the emergency department or has been discharged and this information is sent to the primary care physician. In this scenario, it is more complicated because the hospital or emergency department made decision to send information to the HIE if they had this patient. The HIE is often the place where they make the decision to route information to the primary care physician or other providers, such as specialists or behavioral health providers. Therefore, there is more logic required to send information to multiple end points. In this scenario, they also have to deal with patient matching and which providers are subscribed to get notifications on specific patients. It is more complicated than pushing data to a well-known registry.

The next concept Tim Pletcher discussed is the continuum. At one end is a network of networks model. Traditionally, the primary function of this model is to route data or broker a request for information. For example, find information on an individual patient that is available at multiple hospitals. At the other end of the continuum is a longitudinal medical record, all providers are pushing data to the HIE.

Tim Pletcher indicated that the network of networks model is a nice starting place. It tends to be easier because it is facilitating information routing. Everyone maintains one connection. Additionally, one does not need to worry about what the HIE is doing with the information because they are not keeping all the information in this model. Costs for this model are also lower because it is not creating a longitudinal medical record. Over time, people become confident that the HIE can successfully route information and then want the HIE to do more. This approach is similar to how the internet works. There is not one big pile of data on the internet, there are a handful of services, like Google, which allow one to find information and where it resides in the organization. Allan Hackney has advocated for the network of networks model.

At the other end of the continuum is to have the HIE focus on building a longitudinal medical record Tim Pletcher noted. Once everyone is participating in the HIE, this is a very powerful space to be. The data is available, and one can also perform advanced analytics on top of the longitudinal medical record. This is dependent on consent as well.

Tim Pletcher described pulling information from another endpoint as more complicated. For example, a person goes to a clinic and a provider wants to see the most recent information on the patient. Even in a network of networks model, one wants to find where there is information about the patient. This process is called a record locator. Once one figures out where information lives, he/she has to query information from

those sources, and the sources have to pull it forward. In this case, the entity that is getting queried has to make the decision with regard to consent. The entity has to decide if they can release this information to the requesting provider or organization. This requires heavier infrastructure for record location, ensuring the entity being queried has consent, and then confidence that everyone is talking about the same patient.

Tim Pletcher indicated that one of the nice things of having a virtual longitudinal record is that it simplifies the actual query process. There is a big pile of data to pull from and consent and patient matching decisions happen all in one place.

Generally speaking, Tim Pletcher described that pushing data to a well-known place is easy, pushing data from one place to multiples places is a little more complicated, and pulling data is even more complicated.

Lisa Moon added that HIEs need to be able to do simple things well so that it can do more complex pieces like analytics or longitudinal records further down the road.

Nic Scibelli asked about the continuum. Does it imply there are things in between such as a clinical quality database where the HIE holds some information but not all treatment information?

Tim Pletcher replied absolutely. From his perspective, CT is starting with a network of networks model but is working towards the longitudinal health record. The eCQM database is a great example of being somewhere in the middle for a very specific purpose or use case which is quality measure information. It is defined spot on the continuum.

Tim Pletcher explained that they will start to bring the legal framework into the discussion. The first step is to have organizations legally connect to the HIE. Organizations are signing a master agreement which is either an organization agreement, a simple data sharing agreement, or a terms of service. This is a master document that says the organization promises to “be good” and wants to be a member of this community. There are nuances to these documents. An organization can also sign a use case exhibit. The first step is to join the network and the second step is to execute use case exhibits.

The organization agreements are similar but slightly different. Qualified Data Sharing Organization Agreement (QDSOA) is typically a document that the HIE entity will allow other organizations to make changes to. The organization’s lawyers need to have wording in a certain way and the HIE can accommodate this to a degree. It also creates an opportunity for the organization to be a part of operational governance. The Simple Data Sharing Organization Agreement (SDSAO) does not provide a defined space for operational governance but it is very similar to the QDSOA in every other way. The terms of service is designed to be a fairly automated document, similar to an end user license agreement. The terms of service is often surfaced when the organization is using an application the HIE is providing.

Tim Pletcher made an analogy to container shipping. Historically, people would ship things back and forth in a cargo hole. There are cars, lumber, boxes, tires and many other things in a cargo hole. When you deal with taking these things out, it is very manual, and many people are working to remove the items. Modern container shipping has put items into containers. These items are sealed. One set of very specific product types will go into particular locations. They are handled independently and specifically as they go to docks/locations. This is similar to how he thinks of use cases. Instead of dumping everything into the cargo hole, use cases treat information as discreet containers so people on both ends really know how information will be handled as it goes through the network. Immunizations, encounters, or medications could all be packaged differently based on what people agree upon.

Tim Pletcher reviewed use case components. First, a use case summary is written in language that someone non-technical can read and understand what is being done. The second area is a use case legal exhibit which can be appended to a master agreement. The HIE and all the trusted data sharing organizations sign it. Attached to every legal exhibit is a pointer that references an implementation guide. This spells out what data formats, technical standards, and conformance requirements are necessary to implement the use case.

Use case exhibits are standardized in their format. They include a purpose, diagrams, definitions, primary use, special considerations for service interruptions, responsibilities of parties, special terms unique to the use case and an implementation guide. These are not meant to be long documents; they are fairly concise and get added on to the master/qualifying organization agreement.

Tim Pletcher indicated that there a handful of benefits to adopting a use case approach: reduces complexity, provides a consistent pattern, modular, aligns priorities, transparent, measurable, faster and cost effective.

From a governance perspective, in CT, there are 3 components: State Health Information Technology Advisory Committee, Health Information Network Board, and operational governance committees.

Tim Pletcher explained that the process of birthing a use case and bringing it to mature adoption is called a use case factory. There are many people that may have ideas about what to share, but through this process it becomes clear that certain use cases are more feasible than others. This may be due to institutional will, high priority for funding, or technical barriers. The factory is divided up into stage gates: conceptual, demonstration, implementation, and production implementation.

From a public transparency perspective, Tim Pletcher reviewed the 3 main pieces: Health IT Advisory Council, the entity’s Board and the entity operation advisory committee. The Health IT Advisory Council has many design groups. This Council is formulating big policy, governing principles, and a general framework or approach. However, the entity does not actually work or report to the Health IT Advisory Council although there are synergies. Ideas and recommendations from the Council go to the entity’s board. The entity board is responsible for fiduciary actions of the entity. Then, the entity relies on the operations advisory committee. Organizations are invited to be a part of an operations advisory committee.

Tim Pletcher reviewed the process for operational governance. Beginning with design groups all the way to joint application design sessions. For example, someone on the CDAS team may define what widgets should be on the screen. This creates a process to help advance data sharing or develop a working application. Tim Pletcher further described the flow of use case information between the groups. The HIT Advisory Council may go to the design groups and request more concrete and operational meetings to sort out specific details of a use case. Then, there may be pilots to prove out concepts. There could be working groups that will interact with the committee to determine what goes into legal agreements and specify how the data will move. Ultimately, this will move the use case from pilot to production. Each of the different groups will have a role in the process. The operations advisory committee is helping everyone understand the kind of data that will be shared, passing this up to the Board for sign off, and providing feedback to the HIT Advisory Council for principles related to actionable data sharing. The other piece that an operations advisory group can support is a dispute resolution process.

The last area that Tim Pletcher reviewed is related to sharing protected health information. Out of the gate, CT is really focused on HIPAA and what it allows. He acknowledged, even in HIPAA, there is no “one-size-fits-all.” However, within HIPAA they can develop use cases that fall under treatment, payment and operations. In a legal framework, one of the organizing principles for an initial set of use cases focuses on HIPAA and when there are covered entities with relationships in common with the same person. If two covered entities share a patient, that enables them to share information under a treatment, payment or operations perspective. Using organizing principles and following the HIPAA model, they want to ensure there is a “HIPAA chain of trust.” At no point is information shared outside of this chain of trust.

4.	Overview of May 21, 2019 Meeting	Michael Matthews	1:55 PM
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Tim Pletcher indicated that they will discuss identity, how do they know if they have patients in common, talk through some of the first few use cases envisioned and the role of CDAS versus use cases during the next session.

<p>Nic Scibelli asked to refer back to slide 39. With regard to, “in 5 years when everyone is comfortable,” his understanding is that it is not necessarily about regulations, but comfort level. How much of a barrier will this be in an initial stage?</p> <p>Tim Pletcher indicated that they will not know how much trust exists in the community until they form the operations advisory committee. It could move quickly, but it takes time to build trust. They want to ensure they package the use cases in a way that allows people to know where the guide posts are, as this will help build trust. It will be determined by the first 4 or 5 use cases. Regulation alone will help it move, unless people are really distrustful. The legal framework tries to remove distrust quickly.</p> <p>Nic Scibelli asked if there is an opportunity for an advisory group to prioritize use cases, but then the entity makes a decision that it is not practical. Does entity redefine that for the group?</p> <p>Time Pletcher indicated that in the end, the entity is its own entity and that would probably be sensible. They have seen this happen before if there are technical or liability barriers. Typically, at one of those stage gates in the use case factory, they are making a requirement or providing an incentive to accelerate a use case. Anytime there are financial incentives or penalties, those use cases become prioritized. There are factors outside the HIE which determine the rate of adoption.</p>			
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<p>For the next session, Tim Pletcher indicated that they will start with questions and then discuss identity and care maps.</p> <p>Michael Matthews thanked everyone for their participation and ongoing support.</p>			

Upcoming Meeting Schedule: June 4, 2019; June 18, 2019; July 9, 2019; July 23, 2019